

Behavior Support/Crisis Plan Hierarchy

By Marcia Braden, PhD

People with fragile X syndrome (FXS) are not generally aggressive. There are, of course, exceptions, and we hope that the following information helps caregivers plan appropriate interventions for those instances when aggression is a problem.

It has been our experience that aggressive behavior is usually a direct response to external factors. Clinical experience has provided clear evidence that identifying antecedents prior to aggressive behavioral episodes has significant merit in reducing aggression. In addition, there may be neurobiological factors that contribute to aggression. Therefore, it is always important to confer with a physician about medication.

Aggressive incidents are described by parents, caregivers, and clinicians as a “fight-or-flight” reaction to an environmental or social condition that persists when an accommodation is not afforded. When the condition or antecedent is successfully identified and accommodations are made, the person with FXS can begin to regulate his reaction within a more appropriate context. If the aggression escalates and eventually becomes unmanageable, it is important to follow a crisis plan that will keep the individual with FXS and other personnel safe. Such a plan is outlined below.

BEHAVIORAL INTERVENTION: A THREE-STEP APPROACH

Step One: Responding to Common Antecedents

The first step of any behavior plan is to intervene at the antecedent level as listed below, with redirection, reduced stimulation, and introduction of a distraction or an environmental accommodation.

COMMON ANTECEDENTS

Environmental

- Noisy
- Crowded
- Novel
- Transition-laden

Physiological

- Red face
 - Red ears
 - Covering eyes
 - Sweating
 - Becoming flushed/hot
 - Pacing, excessive movement, hand-flapping
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Social

- Introductions
- Answering/talking on phone
- Receiving compliments
- Direct questions

Step Two: Defusing Aggression

If intervening at the antecedent level is unsuccessful, it is important to institute the initial phase of a crisis management plan to defuse aggression and restore calm to the situation.

- Use fill-in strategies or side dialoguing between two staff members to set the stage.
For example: “We will move the table and then turn down the lights so we can calm down.”
- Remove any environmental obstructions that may become harmful to the client or others.
Have other clients exit the environment.
- Reduce verbal input, remain calm, and keep voice low.

Step Three: Actively Managing Aggression

If aggression continues, discontinue all verbal input, enlist staff support, and follow the active crisis plan and procedural remedy that is sanctioned by the school district or governing agency at your facility. (Note that these procedures vary in different settings, and require knowledgeable and trained staff to fully protect the well-being of the client while also shielding the facility from potential legal liability. This is one more strong argument for having well-trained staff.)

When Agitation Occurs: Using the “3 Rs”

By Jayne Dixon Weber

(Note: There is a vignette on the DVD based on this material.●)

People with fragile X syndrome can sometimes exhibit unpredictable behavior when they get agitated, including becoming aggressive. Here is a strategy—a 3-step plan and reward system, that with slight variations, can be used at home or at work.

REMOVE

First, you want your adolescent or young adult to realize that when he is feeling mad or frustrated, he should remove himself from the situation. This is not punishment—it is a way to deal with negative emotions. You may need to tell him to do it initially, but hopefully, he will come do it himself over time.

RELAX

Second, figure out activities that he finds relaxing. He could listen to music, read a magazine, or draw. Or he might just want to lie on his bed. He should have several options available in his room.

REFOCUS

Third, your adolescent should have a physical activity that allows him to refocus before rejoining the group. He may want to swing, bounce on a therapy ball, go for a bike ride, or go for a walk. Make sure he has more than one choice.

TEACHING THE PROCESS

First, come up with the words you are going to use for the behavior(s) you are targeting. For example, “Go to your room” typically has negative connotations, so try something like, “It is time to relax” or “Looks like you need to go listen to some music.” Feel free to come up with whatever phrase will work in your circumstance and that everyone can be consistent with using.

Explain the whole process and purpose of what you are doing. “Sometimes when you get mad you hit, so we are going to try something new. When I see you get upset, I am going to tell you, ‘It is time to relax.’ I am going to say it one time, and then I am not going to say anything else until you are in your room. You will go to your room for about 10 minutes, where you can listen to music, read a magazine, or do whatever else will help you calm down. Then you will go swing or ride your bike for a while, and then you can come back to what you were doing. This does not mean you are in trouble—this is a way that we have come up with for you to calm down and keep us both safe.”

The very first time you do it, walk through it with him. After you say, “It is time to relax,” both of you go to his room. Make sure he does something he likes while you engage in your own calming activity. After a few minutes, go for a bike ride, and talk about how good it feels.

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Mention how easy this was and how it will be a good thing for everyone in the family to do when they get upset. Then have him go back to whatever activity he was doing.

The next step is to practice actually going through this during a calm time, except he will do it on his own. Initially, you will tell him ahead of time that you are going to say the words, so he knows to expect it. Practice it a few times until you know he has the procedure down.

Continue to have occasional practices without telling your adolescent when you are going to begin the process. Again, practice until you think he has the routine mastered.

If you ever have incidents in the car, you will also want to practice the intervention there. The back seat is a good place to relax, but you will need to adapt this for your vehicle.

Here is one twist to this strategy: There are times when we all need to get our composure. Let your adolescent see you do what you are asking him to do sometimes. "I am feeling upset. I need to go relax. I am going to stay there for a few minutes, then I am going to rock in my rocking chair, and then when I feel better, I will make dinner." He needs to see that others can also benefit from this strategy.

THE REAL THING

After you think you have practiced enough, tell your adolescent that you are finished practicing, and that you are going to do it "for real" when you need to. The only caveat is that if several days pass and there has not been an incident, you may want to practice again, just to keep up the routine. In this case, you will want to tell him ahead of time if you plan to do that.

One day he comes home, is very agitated and raises his voice at you. You respond: "It is time to relax." Remember: do not say anything after you say this. Hopefully, he goes to his room. He may hesitate the first time, but glance or point towards his room if necessary.

After a period when you think he has calmed down (perhaps 10-15 minutes), go to his room and announce: "When you are ready, you can go on the swings or bounce on the therapy ball."

However, if he says anything negative to you, then tell him it looks like he still needs more time. Then walk away. Go back and repeat every 5-10 minutes until he has calmed down. Make sure he does his refocusing activity for 10-15 minutes. The time may vary—you be the judge. Then say, "You can rejoin us when you are ready."

REWARD SYSTEM

Provide a reward system to give your adolescent an incentive to carry on through this process. During all the practice sessions, give him something after he has refocused: a coupon or small amount of money that he can redeem for things he enjoys.

Since what you really want is good behavior all day, try this: Break the day down into three periods—morning, afternoon, and evening. Get a calendar you can devote to this and put three little boxes on each day.

If your adolescent does not have an incident during the morning period, you will put a mark in the appropriate box, and so on throughout the day. For each mark, he gets a token. So if he goes all day without an incident, he will get three tokens at day's end.

If he has an incident during one period and he goes to his room right away, he gets his token right away. If he does not go to his room uneventfully, he does not get his token for that period.

Another thing that you can do during the day is keep track of the good things your adolescent does, particularly as he relates to difficult activities such as transitions and not getting what he wants, when he wants. At the end of the day, talk to him about these things and let him know: "You can do this."

MANAGING RESISTANCE

Your adolescent's refusal to go to his room could be a problem. Depending on his level of agitation or aggression, the best idea is for you to leave the room if he will not. If you think his behavior may escalate, take yourself completely out of the picture, move to another room and say, "It is time to relax, and if you aren't going to go to your room then I will leave. When you are ready to follow the plan, you can let me know." From a distance, check back with him after a few minutes. Continue to do so until he is ready to comply with the plan.

ADAPT, MODEL, DISCUSS

It all boils down to the 3 Rs. This is a relatively simple concept to implement and is easily adaptable to most families. The difficult part is keeping the intervention from seeming like punishment to your adolescent, but keep modeling it yourself and talking about personal responsibility. If his behaviors do not stop or continue to escalate, be sure you talk to his psychiatrist or other mental health professional for more ideas.

Note: Our family worked with Partners in Behavioral Milestones, Inc. (see Resources, page 14) to develop a plan similar to this for our son Ian.

Reward Systems

Developed by the Project Work Group

Goal: For your child of any age to exhibit good behavior.

THE BASICS

Any reward system you devise has to be:

- 1) One your child understands.
- 2) Motivating (he or she has to buy into it).
- 3) One that *you* can follow on a consistent basis.

As you develop your reward system, here are some other ideas to keep in mind:

- Make sure your child knows what behavior you are expecting. It is easy to say “No” and “Stop it,” but does he or she know what “to do” instead?
- Develop a reward you think your child will be willing to work for at least in the beginning. Consider money, tokens, and doing special activities (watching a movie, getting ice cream).
- Know that most reward systems will have to change or adapt over time. Your child may get tired of receiving money (!) or tokens for good behavior.
- Some children will not have a concept for getting money/tokens and then saving to buy something. In those cases, you may want to provide an actual item as the incentive each time—such as a baseball card.
- Depending on your child, you may also want to have a “bigger” gift available when he or she achieves targeted behavior a certain number of times.
- Once you know what you want your child to do, when he is supposed to do it, and the rewards he will get for doing it, talk to him about it.
- Practice as much as you think you need to during calm periods, and reward her for successful practices.
- Give your child money or a token every time he exhibits the targeted behavior. Make sure you provide regular opportunities to spend it.
- Over time, you may be able to wean her from material rewards, with only verbal acknowledgement of her good behavior. The goal of all reward systems is to make the desired behavior self-rewarding and intrinsically motivating.
- Realize that this process may take a long time and will likely entail many frustrating moments. Be patient and creative.

For other ideas, consider an Internet or bookstore search for children’s behavior reward systems. You may find ideas for children who are “typical” that can be modified to meet your child’s needs.

Behavior at Home: A Few Simple Changes

Developed by the Project Work Group

1. Follow a routine.
2. Use a picture schedule.
3. Develop a method to inform of transitions to come.
4. Allow adequate time to make transitions.
5. Maintain a “sensory diet” throughout each and every day.
6. Participate in regular/daily physical activity.
7. Provide healthy food at regular intervals throughout the day.
8. Minimize unexpected loud noises and be aware of “background” noise in and around your home (lawnmowers, fans, traffic, trains, TV/radio, etc.).
9. Arrange opportunities to schedule your child’s preferred activities.
10. Purchase soft, cotton clothing (often thrift stores are a great source).

Many of these suggestions will require you to experiment with your young adult to see what works best for him or her. Remember, too, that just because it works one day does not guarantee it will work the next! Many variables can influence the routine of a day: illness, a sudden plumbing problem, poor weather, an unexpected phone call, an invitation to do something new and exciting. And don’t forget that some days both you and/or your child are just plain tired!

Do the best that you can, but know that most days will not be perfect. That is okay, because as your child matures, he must eventually learn to live in an imperfect world. It is your job to help him learn to do adapt to these imperfections over time.

PICTURE SCHEDULES

Picture schedules can be an important part of your young adult’s life. He will most likely need some sort of picture schedule for the rest of his life. Here are some ideas:

There are many options for the “picture.” For some, words may suffice: “Soccer @ 4 p.m.” Actual photos are another option, though it can be time-consuming and expensive to implement. “Pecs” is another option: icons that represent a word. There are several websites where you can download these icons for free (see reference section below). You can always draw your own picture. In cases where you cannot find an icon, this is a good option.

Try a desk calendar (approximately 18” x 24” size) that has room to write information for each day. Put it on your refrigerator and use whatever format your young adult prefers—words or

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pictures. You may also want to keep track of other family members' activities; use a different color for each person.

If you prefer more detail, try a three-ring binder and use heavy sheets as in a magnetic photo album. Put the times on the left and use Velcro to attach the activities on the right so they can be changed on a daily basis.

Know that a picture schedule may work one day, while it may not seem to make any difference the next. Or one day a certain type of schedule may work, and the next you may need to modify it with more detail. Have fun with this!

REFERENCES

- Beyond Autism Pecs Pictures/Icons Pages www.members.tripod.com/trainland/pecs.htm
 - www.dotolearn.com/
 - www.kidaccess.com/html/
- Or search by "pecs" on the internet.

SENSORY DIET

A sensory diet can be very important for young adults and, indeed, throughout their lives. Like a nutritional diet, it refers to a carefully planned program that helps individuals manage their sensory input so they are not put on "overload." Read up on the topic, talk to a trained occupational therapist, and see if it makes a difference. Many of the activities are also good for premutation carriers of the Fragile X gene.

REFERENCES

Raising a Sensory Smart Child: The Definitive Handbook for Helping Your Child with Sensory Integration Issues. Lindsey Biel and Nancy Peske, New York, Penguin, 2005.

Sensory Diet Activities for Home and Away: www.sensorysmarts.com/diet.html

The ERIC Clearinghouse on Disabilities and Gifted Education (ERIC EC)

The Council for Exceptional Children

1110 N. Glebe Rd. Arlington, VA 22201-5704

800-328-0272

Understanding Sensory Integration

<http://ericec.org/digests/e643.html>

The National Fragile X Foundation

www.FragileX.org

The Out-of-Sync Child Has Fun: Safe Activities for Home and School: Sensory-Motor, Appropriate, Fun, and Easy

Carol Stock Kranowitz

Penguin Group (USA), 2003

Out-of-Sync Child: Recognizing and Coping with Sensory Processing Disorder

Carol Stock Kranowitz

Penguin Group (USA), 2006

Sensational Kids

Lucy Jane Miller, PhD, OTR

G. P. Putnam & Sons, New York , 2006

Sensory Integration and the Child

25th Anniversary Issue

A. Jean Ayres, PhD

Western Psychological Services, 2005

Resources

Books—The following books are available from The National Fragile X Foundation (800-688-8765, www.FragileX.org).

Braden, Marcia L. *Fragile: Handle With Care, Understanding Fragile X Syndrome*, Avanta, 2000.

Hagerman, Randi J. MD and Paul J. Hagerman, MD, PhD, *Fragile X Syndrome: Diagnosis, Treatment, and Research*. Third Ed. Baltimore: The Johns Hopkins University Press, 2002.

Harris-Schmidt, Gail and Fast, Dale, *The Source for Fragile X Syndrome*, 2004.

Michael Tranfaglia, MD, *Medication Guide for Fragile X Syndrome*. FRAXA Research Foundation, 2000.

Websites—

Applied Behavior Analysis (ABA)

Cambridge Center for Behavioral Studies

www.behavior.org/ (there are numerous websites on this topic—talk to your doctor)

The National Fragile X Foundation

www.FragileX.org > intervention > behavioral disorders

Partners in Behavioral Milestones, Inc. (PBM, Inc.)

6412 E. 87th St.

Kansas City MO 64138

816-501-5138

www.behavioralmilestones.com/

Disability Solutions

www.disabilitysolutions.org/

Click on “Newsletters,” search for “Behavior”
